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Running head: Body image and spinal cord injury

Body image in persons with spinal cord injury, during inpatient rehabilitation.

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No conflict of interest is reported.

Body image in persons with spinal cord injury, during inpatient rehabilitation.

Objectives: To investigate the course of body image in persons with spinal cord injury (SCI), during their first inpatient rehabilitation stay. Moreover, to explore the association between

demographic and injury-related variables and body image, and between body image and psychological distress.

Design: Longitudinal inception cohort study.

Setting: Rehabilitation center Sint Maartenskliniek in Nijmegen, the Netherlands.

Participants: From 210 people admitted for the first inpatient SCI rehabilitation program, between March 2011 and April 2015, 188 met the inclusion criteria, and 150 (80%) agreed to participate.

Interventions: Not applicable.

Methods: Self-reported questionnaires to assess demographics, injury-related variables, body image and psychological distress were completed in the first week after admission and in the week before discharge.

Main outcome measures: The Body Experience Questionnaire (BEQ) was used to measure two dimensions of body image: Alienation and Harmony.

Results: Mean scores on the Alienation scale decreased significantly during the rehabilitation program. Mean scores on the Harmony scale did not increase significantly, but showed a trend in the hypothesized direction. . The two scales showed weak correlations with demographic and injury-related variables. The two scales together explained 16% and 14% of the variance of depression and anxiety respectively, after correction for demographic and injury-related variables.

Conclusion: During the first inpatient rehabilitation stay after SCI, the course of body image increases towards a healthier state. Body image explains parts of the variance in depression and anxiety and can be a target of interventions by the whole rehabilitation team.

50 **Key Words:** spinal cord injuries, body image, body-mind relations, psychological factors,
51 rehabilitation

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54 Abbreviations:

55 AIS: ASIA Impairment Scale

56 ASIA: the American Spinal Injury Association

57 BEQ: Body Experience Questionnaire

58 HADS: Hospital Anxiety and Depression Scale

59 QoL: Quality of life

60 RD: Rheumatic diseases

61 SCI: Spinal cord injury

62 VAS: Visual analogue scale

Introduction

A spinal cord injury (SCI) involves changes in motor activity and movement patterns, as well as sensory input.¹ Depending on the height and completeness of the SCI more limitations may occur.¹ Furthermore a number of secondary complications, like pain and fatigue, affect the well-being of people with SCI.² Influenced by both physical and psychological aspects, changes can occur in the person's body image after SCI.³⁻⁵ According to the cognitive behavioral perspective,⁶ body image refers to the multifaceted psychological experience of embodiment, especially but not exclusively one's physical appearance. It encompasses one's body-related self-perceptions and self-attitudes, including thoughts, beliefs, feelings and behaviors. Within this framework, negative body image experiences unfold as the cumulative result of developmentally predisposing influences and specific events that provoke and sustain maladaptive processes.⁷ Being confronted with SCI, but also with its complications, can be seen as such specific events. Further this framework state that different facets of body image are associated with psychosocial functioning and emotional stability.⁸

Most of the studies into body image of people with SCI focus on physical characteristics and/or physical activity.^{3,4,9-15} From these studies it becomes clear that SCI has consequences for the way people with SCI perceive oneself and interact with their surroundings, including potential partners.^{4,10,12,13} Other studies suggest that the satisfaction with the body improves over the years after SCI.^{3,12,15} The age at injury does not seem to have any influence.¹¹ Some studies found that the satisfaction with appearance after SCI was not different from a reference group.^{9,14}

One way to study body image from a cognitive behavioral point of view is to explore how people experience the relationship between their body and self. According to Bode,¹⁶ this experience consists of two different aspects, namely Alienation and Harmony. Alienation can be understood as a split between the body and the self, whereas Harmony is indicative for the degree in which the body is considered as a partner of the self. In healthy conditions, it is assumed that body and self are in Harmony.^{5,17} This Harmony can be disturbed by a chronic condition.^{5,13,16,17} Due to a chronic condition or complications like pain and fatigue, the patient can be aware of the difference between the body and the self.^{16,17} This process is referred to as a body-self split or Alienation.¹⁶ So far, Alienation and Harmony have only been studied in other diagnostic groups.^{16,18} To date, it is not known if this disturbance of Alienation and Harmony also occurs in people with SCI.

Studies in other diagnose groups and healthy people found a positive correlation between body image and quality of life (QoL).^{19–21} Also in studies with SCI, body image seems one of the factors contributing to QoL.^{3,9,12,22} Although some of the former studies in SCI suggest a relationship between body image and emotional aspects of adjustment to SCI,^{4,9,10,22} none examined this relationship explicitly. To our knowledge, there are no studies investigating body image during the inpatient rehabilitation phase, nor are there any studies about the possible influence of body image on the experienced distress of people with SCI.

The aims of this study are: a) to describe the course of body image during the first inpatient rehabilitation stay after the onset of SCI; b) to explore the associations between demographic and injury-related variables and body image; and c) to explore the associations of body image with psychological distress, controlling for the influence of injury-related variables and demographic factors at discharge.

Our hypotheses; a) during inpatient rehabilitation the mean Alienation scores will decrease, while the Harmony scores will increase. In other words; the participants will go to a more healthy state of body image; b) body image is associated with injury and demographic variables; having more severe SCI and more complications are associated with more Alienation and less Harmony; and c) in line with Cash's theory we hypothesize that body image is associated with psychological distress, after correction of demographic and injury-related variables.

Methods

Participants

All people with SCI, admitted for their first inpatient rehabilitation stay to the Sint Maartenskliniek in Nijmegen, between March 2011 and April 2015, were considered for inclusion in the present study. In this period a total of 210 people with SCI were admitted for their first rehabilitation. People with cancer-related SCI with a short life expectancy could not enrol in this study. Further, people were excluded from this study if they were delirious during the first week of admission, had severe psychiatric, cognitive or intellectual problems, or if they were not sufficiently able to read Dutch according to the rehabilitation physician and the ward psychologist. Admitted patients receive physiotherapy and occupational therapy on a daily basis, and at least an intake with a social worker and psychologist. Psychological treatment is given when indicated after this appointment. An average inpatient rehabilitation program consists of 12,6 hours of therapy a week. The average stay on this ward is 90,7 days. A stay of 21 days or less, for the first SCI rehabilitation, is considered as short.

Procedure

The ward psychologist contacted the people with SCI in the first week of their admission and asked them to complete a set of psychological questionnaires for diagnostic purposes, as part of routine care. During that same appointment, potential participants were informed about the purpose and contents of this study. It was explained to them that enrolment in the study would mean that their responses would be used for research purposes, and that they would be asked to complete the same set of questionnaires in the week before discharge. Participants with a short stay, were asked if they would complete the discharge questionnaire, if they stated that there were little or no changes they did not. If the participant was not able to write because of hand function problems, they were asked to complete the questionnaires with help of a partner or other trusted person. If no one was available, a clinical psychologist's assistant supported them. All participants gave written informed consent. The local medical ethics committee approved the research protocol. For the present study, only cases with complete data on admission and discharge were analysed.

Measures

Demographics. Age, sex, living with a partner, educational level and work were assessed.

SCI characteristics. Time since injury; cause of the lesion: divided into traumatic (traffic accident, industrial accident, sports accident, fall from height and gunshot – or stab wound) and non-traumatic (disease related or resulting from medical procedure); level and type of injury according to the American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A, B, C or D of the SCI were determined by a trained rehabilitation physician.

Pain. Pain was measured with a visual analogue scale (VAS 100mm).

Fatigue. Fatigue was measured with a visual analogue scale (VAS 100mm).

Body image. Body image was measured using the Body Experience Questionnaire (BEQ).¹⁶ Given the lack of validated measures of body image in SCI, the BEQ was chosen given its length and face validity for the concept we were attempting to assess. The BEQ contains 10 statements, of which 6 form the subscale Alienation. This subscale captures the situation in which the body and self are split from each other. The other 4 statements form the subscale Harmony, which is indicative for the degree in which the body is seen as a partner of the self.¹⁶ Respondents were asked to what degree they agreed with each statement on a 4 point scale, ranging from 1 (totally disagree) to 4 (totally agree).¹⁶ In a previous study in people with rheumatic diseases (RD), both scales had acceptable to good internal consistency (Alienation $\alpha=0.84$; Harmony $\alpha=0.76$).¹⁶ In this same study a strong negative correlation was found between Alienation and self-esteem, and moderate positive correlation with Harmony and self-esteem. Also strong positive correlations were found for Alienation with functional limitations and helplessness and a moderate with pain intensity. The BEQ fully mediated the relationship of functional limitations and self-esteem. Illness cognitions were able to partially mediate this relationship. In the present study, Cronbach's α of the Alienation scale was 0.81 and 0.84 at admission and discharge, respectively, and α of the Harmony scale was 0.63 and 0.64, respectively. The factor analysis was repeated and resulted in almost the same two factor structure as described by Bode et al..¹⁶ The Eigenvalues of Alienation and Harmony are 3.65 and 1.56 respectively, and all item showed factor loadings higher than .55 on the expected factor. Only question 10 (see table 2) did also load on the unexpected factor (-.48). We accepted this difference.

Distress. We assessed distress using the Hospital Anxiety and Depression Scale (HADS). The HADS is a commonly used measure of distress and contains 14 statements with 7 items each measuring depressive mood or anxiety. Respondents were asked to what degree they agreed with each statement on a 4 point scale.²³⁻²⁵ The Cronbach's alpha for the HADS scales on both measurements are between . 82 and . 83.

Statistical analyses

The sample was described by numbers and percentages for categorical variables, and means and standard deviation (SD) for continuous variables.

Because of the non-normal data distribution (according the Shapiro-Wilk test) and the ordinal measurement levels, non-parametric tests were used. Changes in scores between admission and discharge were analysed using Wilcoxon signed ranks tests. Because body image scores changed during rehabilitation, we used the discharge data to analyse associations between the BEQ scores and demographic, SCI-related, and psychological distress variables. Associations were expressed in Spearman correlations for continuous data and in eta for categorical data; correlations till 0.3 are considered as weak, between 0.3 and 0.5 as moderate and above as strong.²⁶ To examine the independent associations between BEQ scores and the psychological distress measures, hierarchal regression analyses were performed. Preliminary analyses to check for violations of the assumptions of normality, outliers, linearity, multicollinearity, and homoscedasticity were performed. All demographic and injury-related variables were entered simultaneously in the first block and the two BEQ scales were entered in the second. The percentage of variance (R^2) were computed. Values of R^2 below 0.25 are considered as small associations, from 0.25 till 0.40 as moderate and above as large.²⁶ P values less than

212 0.05 were considered statistically significant. All analyses were conducted using SPSS
213 statistical program for Windows (version 23) (IBM corp, Armonk, NY).

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Results

Of the 210 people with SCI admitted during the inclusion period, 8 did not speak or read Dutch, and 14 had cognitive or intellectual problems that made it impossible to complete the questionnaires in a reliable way. Of the remaining 188 persons, 150 (80%) agreed to participate in this study. At discharge, 10 patients did not return the questionnaire, of whom 6 had been admitted for only a short period of time (< 21 days). A further 6 participants missed one or more items. Table 1 displays the characteristics of the sample, with a complete dataset (N=134).

Insert Table 1

The differences between the participants with and without complete data were not significant. The mean age in this sample was relatively high, and relative few people had a paid job at the time of the SCI, in part because many were in (early) retirement.

Table 2 shows the 10 BEQ questions and the response distributions, dichotomized into Disagree (1 “totally disagree”; 2 “disagree”) and Agree (3 “agree” and 4 “totally agree”), at both test occasions.

Insert Table 2

Table 3 shows the score distributions of the main variables at admission and discharge. The mean score on Alienation decreased significantly during admission. The mean Harmony score increased but not significantly. The pain, fatigue and distress scores all decreased significantly between admission and discharge.

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Insert Table 3

In table 4 the correlations coefficients are depicted between the determinants and the distress and body image variables at discharge. Higher scores on the BEQ Alienation scale were weakly associated with female sex, complete SCI, and higher pain and fatigue. There was a moderate positive correlation with the duration of stay. The Harmony scale was only, and weakly associated with these last three variables.

There was a strong positive association between Alienation and depression, and a moderate positive association between Alienation and anxiety. There were moderate negative associations between Harmony and the HADS scales.

Insert Table 4

Table 5 shows the results of the regression analyses with the distress scales as dependent variables. All demographic and injury-related variables together explained a moderate 32% of the variance of both HADS scales. The BEQ scales together explained an additional 16% and 14% of the depression and anxiety scales, respectively.

Insert Table 5

Discussion

This is the first longitudinal cohort study into body image of people with SCI during their first inpatient rehabilitation stay. During this period the average body image scores improved towards a more healthy state. Body image was positively associated with completeness of SCI, secondary conditions, duration of stay, and sex. Most importantly, body image explained a small but significant amount of the variance of the distress variables, after correction for demographic and injury-related variables.

As expected, levels of Alienation were significantly higher at admission compared to discharge. The levels of Harmony increased during rehabilitation, also as expected, but this change was not significant. These results show that body image changes towards a more healthy state during inpatient rehabilitation. This finding corroborates earlier studies in the chronic phase, which shows, that over time, people with SCI seem to adjust to their changed bodies.^{3,4,15,27}

Our hypothesis that Alienation and Harmony would be associated with demographic variables was only partly confirmed. Associations between Alienation and Harmony and the injury-related variables were stronger. Overall, there were more and stronger correlations with the Alienation scale compared to the Harmony scale. These findings correspond with the study of the BEQ by Bode et al..¹⁶ Based on these differences, they concluded that both scales reflect divergent concepts. However, an alternative explanation could be that the Harmony scale is not as sensitive to change because of its lower Cronbach's α in this study. The association between body image and the severity of the physical impairment and secondary conditions, also corroborate earlier studies.^{15,16} The weak associations of Alienation and Harmony with functional impairment and secondary conditions can be understood by the cognitive behavioral model of body image.^{3,6} This multi-dimensional paradigm considers all the

constructs that may be related to the development of body image. The BEQ only measures a part of the cognitive and affective aspects of body image. The finding that women report more Alienation, may be caused by the fact that appearance is, in general, more important for women than for men.³

The Alienation and Harmony scales together explained a unique 16% of the variance of depression. This is comparable to percentages found for other psychological constructs, such as locus of control ($\Delta R^2=0.16$)²⁸ and self-efficacy ($\Delta R^2=0.18$)²⁹ after correction of some disability related variables or demographic variables, although much lower than sense of coherence ($\Delta R^2=0.33$).²⁹ In the same study Kennedy et al.²⁹ found for sense of coherence comparable percentage of explained variance of anxiety ($\Delta R^2=0.12$) as we did for body image.

In this population the mean of the Alienation score at discharge, was equal to the mean found in an earlier study in community dwelling people with RD. The mean score of the Harmony scale at discharge stayed significantly lower than what was found in that earlier study.¹⁶ Since RD and SCI are two very different conditions, these similarities and differences are hard to interpret. Bode et al.¹⁶ speculated that the Harmony scale can be seen as an indicator of successful coping with functional impairment rather than Alienation, which can be seen as a measure of the direct relation between body and self. If this is correct, then the rehabilitation phase may be long enough to decrease the feeling that the body and self are two different phenomenon although not long enough to successfully cope with functional impairment. However further research, for instance one year after inpatient rehabilitation, would be necessary to test this hypothesis. Another explanation for the non-significant change in the mean Harmony score can be found in the scale itself. The internal consistency of the

Harmony scale was low in this population. The Harmony scale may not be a reliable measure to detect changes during this period of time.

Clinical implications

This study showed a course of body image towards a more healthy state during the first rehabilitation phase. Decreases in pain and fatigue scores, which were found in the present study, may be of influence on this positive course.¹⁶ Further, participants gain a lot of experience with their changed bodies during rehabilitation,²² due to all physical (training) activities, sports, learning to perform self-care, and other activities of daily living. All disciplines of the rehabilitation team play a role in this process of improving the person's body image, and as a result minimize feelings of depression and anxiety. In this respect, the physical disciplines may do more on the way people look at their selves than they may be aware of.⁴ A simple instrument like the BEQ to measure body image can help to identify people experiencing (problematic) Alienation. These people can be assigned for a cognitive behavioral therapy program for body image, which is an evidence-based therapy for body image disturbances.^{21,30}

Study limitations

The validity of the BEQ has not been extensively examined in earlier studies, further research is needed to establish this. With respect to the reliability of the Harmony scale; in this population the internal consistency was low. This is most likely based on the small number of items, since the mean inter-item correlation was sufficient. To draw stronger conclusions about the course of body image over time, a longer follow-up period, for instance one year after discharge, is needed. The study sample is representative for

people with SCI in inpatient rehabilitation in the Netherlands, but compared with the international literature,^{31–34} this sample is relatively old, and contains a higher proportion of females, which may have an impact on the body image scores.

We do not know what the influence may have been of filling out the questionnaire with help from a proxy. Furthermore, we did not gather information about the contents of the rehabilitation program. Nor did we have information about other secondary conditions than pain and fatigue and about other psychological constructs, that may be of influence on body image,^{10,13,15} nor about the premorbid body image.

Conclusion

Body image changes towards a more healthy state, during the first inpatient rehabilitation stay after the occurrence of SCI. Body image explains a small but significant amount of the variance of both depression and anxiety, after correction for demographic and injury-related variables. Positive changes in body image and psychological distress, may be the result of the efforts of the whole multi-disciplinary rehabilitation team.

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438 **Table 1. Details of participants with a complete dataset (N=134) at admission**

	Mean (SD)	Range
	N=134	
Age (years)	54.2 (15.2)	20-88
Duration of injury at admission (days)	31.5 (33.9)	0-220
Duration of stay (days)	95.3 (53.0)	16-309
	Frequency	%
Sex (male)	86	64.2
Injury level		
Cervical	55	41.0
Thoracic	55	41.0
Lumbo-sacral	24	17.9
Completeness		
AIS A	38	28.4
AIS B	14	10.4
AIS C	26	19.4
AIS D	56	41.8
Cause of injury (traumatic)	56	41.8
Living with a partner	102	76.1
In paid employment before SCI	56	41.8
Education level		
Higher education	35	26.1
Medium education	60	44.8

Lower education	39	29.1
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439 **Higher education = College or university**

440 **Medium education = High school**

441 **Lower education = Secondary school or less**

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Table 2. Distribution of answering on the BEQ questions on both measurements (N=134)

		Percentage	
		agree	
Alienation		T1	T2
2	My body is a burden to me	59.7	42.5
3	It feels as if my body doesn't belong to me	47.0	29.1
4	I don't feel complete	58.2	44.0
6	My body is unpredictable	64.9	50.7
7	I feel betrayed by my body	29.1	24.6
8	I would like to have a different body	37.3	29.1
Harmony			
1	I reflect on what is good for my body	91.0	93.3
5	My body lets me know what is good for me	70.1	78.4
9	I am sensible to my body	78.4	84.3
10	My body feels familiar to me	59.0	56.7

Table 3. Mean and SD at admission and discharge for the BEQ scales, pain, fatigue and the psychological distress scales, and the Z-value according to the Wilcoxon signed ranks tests

	Admission		Discharge		Wilcoxon	
	Mean	SD	Mean	SD	Z-value	P
BEQ						
Alienation (range 6-24)	14.3	4.7	12.5	4.7	-4.79	<0.001
Harmony (range 4-16)	11.8	2.6	12.2	2.3	1.95	0.052
Injury-related variables						
Pain (VAS)	29.6	25.2	20.1	21.9	-4.82	<0.001
Fatigue (VAS)	53.5	24.6	39.0	23.1	-5.33	<0.001
Psychological distress						
Depression	7.4	4.5	5.7	4.0	-5.34	<0.001
Anxiety	6.7	4.3	4.7	3.7	-5.66	<0.001

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Table 4. Spearman correlation coefficients between the determinants and the distress and body image variables, at discharge (N=134). For the categorical demographic variables the measure of association is expressed as eta, instead of the Spearman.

	Depression	Anxiety	Alienation	Harmony
1. HADS Depression	###			
2. HADS Anxiety	0.70**	###		
3. BEQ Alienation	0.52**	0.47**	###	
4. BEQ Harmony	-0.41**	-0.38**	-0.45**	###
5. Higher age	0.17	0.16	0.12	-0.15
6. Sex (female) (eta)	0.04	0.08	0.18*	0.10
7. Having a partner (eta)	0.09	0.14	0.04	0.16
8. Higher education (eta)	0.15	0.21	0.19	0.12
9. Having a paid job (eta)	0.21*	0.15	0.13	0.13
10. Having a complete SCI (eta)	0.12	0.09	0.29**	0.12
11. Traumatic (eta)	0.06	0.14	0.01	0.06
12. Higher level of SCI	0.03	0.04	0.02	-0.10
13. Duration of stay	0.24**	0.18*	0.37**	-0.25**
14. Pain (VAS)	0.31**	0.34**	0.24**	-0.18*
15. Fatigue (VAS)	0.45**	0.44**	0.28**	-0.21*

* p<0.05, ** p<0.01 according to Spearman correlation analyses or based on the ANOVA for the eta

457 **Table 5. Regression analysis with the HADS scales as dependent variables, entering in the first block the demographic and SCI-related**
 458 **variables and the BEQ scales in the second. R^2 (change) is depicted for each group of variables, corrected for the variables in the**
 459 **previous block (N=134)**

	HADS DEPRESSION						HADS ANXIETY					
	Model 1			Model 2			Model 1			Model 2		
	B	SE	BETA	B	SE	BETA	B	SE	BETA	B	SE	BETA
Age	0.01	0.02	0.05	0.00	0.02	0.01	0.03	0.02	0.14	0.02	0.02	0.10
Sex (female)	-0.62	0.72	-0.08	-1.29	0.65	-0.16	0.98	0.67	0.13	0.44	0.61	0.06
Having a partner	-0.48	0.71	-0.06	-0.18	0.65	-0.02	-0.64	0.65	-0.08	-0.31	0.60	-0.04
Level of education	-0.26	0.21	-0.10	-0.34	0.19	-0.13	-0.28	0.19	-0.12	-0.36*	0.17	-0.15
Having a paid job	-1.33	0.72	-0.16	-1.26	0.64	-0.15	-0.13	0.66	-0.02	-0.07	0.59	-0.01
Having a high SCI	-0.08	0.05	-0.15	-0.07	0.04	-0.13	-0.07	0.04	-0.14	-0.06	0.04	-0.11
Having a complete SCI	-0.26	0.29	-0.08	-0.39	0.26	-0.12	-0.25	0.27	-0.08	-0.34	0.24	-0.12

Traumatic SCI	0.18	0.74	0.02	0.35	0.66	0.04	1.38*	0.68	0.19	1.55*	0.61	0.21
Duration of stay	0.02**	0.01	0.24	0.01	0.01	0.08	0.02*	0.01	0.22	0.01	0.01	0.07
Pain	0.03*	0.02	0.18	0.02	0.01	0.11	0.03	0.01	0.16	0.02	0.01	0.10
Fatigue	0.06**	0.02	0.32	0.04**	0.01	0.24	0.05**	0.01	0.32	0.04**	0.01	0.24
R ²			0.32**						0.32**			
Adjusted R ²			0.25						0.26			
BEQ Alienation				0.33**	0.07	0.39				0.25**	0.07	0.32
BEQ Harmony				-0.27*	0.13	-0.15				-.031*	0.12	-0.19
R ²						0.48						0.46
Adjusted R ²						0.42						0.40
R ² Change						0.16**						0.14**

460 B = unstandardized Beta; SE= Standard Error; BETA= standardized Beta. * p<0.05, ** p<0.01

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